Exploring the Use of Quarterly Monitoring Reports in the STOP HIV/AIDS Initiative. A mixed method study

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by

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CAPSTONE PAPER

MASTER OF PUBLIC HEALTH, SIMON FRASER UNIVERSITY, 2016

CAPSTONE PROJECT SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTERS OF PUBLIC HEALTH

IN THE FACULTY OF HEALTH SCIENCES

SIMON FRASER UNIVERSITY

2016

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Acknowledgements

I would like to express my sincere gratitude to the BC Centre for Excellence in HIV/AIDS for providing support and funding for the study and the opportunity to do my practicum. I would further like to thank the key informants from all the Health Authorities, the PHSA and PAN for generously contributing their time and knowledge to this study. I would also like to thank Dr. Rolando Barrios and Irene Day for their support and guidance. I also thank Michelle Olding for her support, revision and feedback throughout the research project.

In addition, I would like to sincerely thank my senior supervisor Dr. Bohdan Nosyk for the support, advice, suggestions, valuable comments and for providing me with the opportunity to embark on this research project.

Abstract

This study aimed to explore the use of quarterly monitoring reports by STOP HIV/AIDS representatives from all Health Authorities in British Columbia. The STOP HIV/AIDS project is a provincial initiative that aims to reduce the burden of HIV/AIDS in British Columbia. The study deployed in-depth interviews with twelve key informants and a ten survey questionnaire to deepen our understanding of the usefulness and the role the quarterly monitoring reports play in informing program planning. The findings found reports to be useful to end-users and provide many benefits including evaluating progress, informing decision-making and a tool to compare work across Health Authorities. Findings also suggest changing the format of the reports, adding more indicators and providing a high level summary page of the report. Overall, informants found the report to be useful for monitoring progress, a tool to compare across Health Authorities and a rich source of data to refer to.

Introduction

Purpose of report

This capstone project is a mixed method study exploring the role that STOP HIV/AIDS surveillance reports and their performance indicators play in informing policy decisions in British Columbia. This capstone aims to provide a deeper understanding of the significance of surveillance reports to Health Authority stakeholders and conclude with recommendations on how to improve the surveillance reports to better meet user needs. The report will begin with a literature review on the purpose, role and significance of public health surveillance systems in general and then put into context with HIV/AIDS and the STOP HIV/AIDS quarterly reports. The mixed methods used in this study and results of the study will also be discussed. Finally, the recommendations and the implications of this study along with future research goals will be addressed.

Background on STOP HIV/AIDS project

In 1981, the Center for Disease Control and Prevention first reported cases of AIDS in parts of the US (Morrison, 2001). 35 years later, 71 million people have been infected with HIV and approximately 34 million have died of HIV (UNAIDS, 2016). The pandemic has disproportionately affected different populations and regions globally. In North America the HIV/AIDs epidemic is more prevalent in injection drug users (IDU) and males who have sex with males (MSM) than the rest of the population. (Morrison, 2001).

Like other countries, Canada and more specifically, British Columbia has been adversely affected by HIV/AIDS since the early 1980's (Montaner, 2006). At the height of the epidemic in the 1990s, one British Columbia was dying a day from AIDS (McInnes, 2009). The first rise in

HIV/AIDS cases occurred in mid-1980's and largely affected the MSM community. Later in the mid 1990's, there was a rapid increase in HIV cases affecting IDU and female sex trader workers (McInnes, 2009). In British Columbia, the majority of HIV/AIDS cases continue to arise through MSM and IDU transmission. Although similar patterns of the epidemic in IDU and MSM were observed in other large cities in Canada including Montreal and Toronto, Vancouver has the largest populations of high-risk individuals, injection drug users (McInnes, 2009).

However, after the introduction of HAART treatment in 1996 AIDS related mortality was reduced by about 85% in a three year span (BC-CfE, 2014). As of 2015, British Columbia accounts for about 13% of new HIV cases in Canada and those numbers continue to decrease (Catie, 2015). BC has been able to reduce the spread of HIV, through the implementation of innovative prevention strategies and harm reduction initiatives (BC-CfE, 2014). Despite these advances, gaps along the continuum of HIV care remain; approximately a quarter of HIV-positive individuals are unaware of the sero-status and less than half of all HIV-positive individuals in BC are receiving HAART treatment (Heath, 2014)

Ever since the introduction of combination anti-retroviral treatment (also known as Highly Active Antiretoviral Therapy) in the 1990's the treatment has been suspected to play a key role in prevention of HIV transmission. More specifically, after the introduction of highly active antiretroviral therapy (HAART) in 1996 there has been a substantial reduction in AIDS-related admission and morbidities globally (Montaner, 2006; Montaner, 2014). This paved the way for applying HAART treatment as prevention (TasP). TasP is a UNAIDS and World Health Organization endorsed concept that has the potential to significantly alter the epidemic worldwide. The concept stems from evidence that drug treatment lowers the amount of virus in the body – improving the health of those on the treatment, lowering the amount of virus in the community and preventing transmission of HIV infection through viral suppression (BCMOH, 2012).

Evidence on the effect of HAART on HIV transmission first arose from studies on vertical HIV transmission from mother-to-child (De Cock KM, 2000). Clinical trials have shown that reducing the mothers HIV concentrations in HIV transmission with HAART treatment decreases the HIV transmission to the child (De Cock KM, 2000). The expansion of HAART availability subsequently led to profound decreases in vertical HIV transmission (De Cock KM, 2000).

Clinical trials in heterosexual couples also found similar results. A prospective study among 3381 serodiscordant heterosexual couples in 7 countries in Africa examining HAART use and HIV-1 transmission reported that ART use by the infected person was associated with a 92% reduction in risk of HIV-1 transmission to their partner (Donnell, 2010). In addition, an ecological study in Taiwan also provided evidence of the effect of HAART treatment on prevention of HIV (Fang, 2004; Montaner, 2006). Similar results were found in population based observational studies in San Francisco (Das, 2010). The study reported a 53% reduction rate in the number of new HIV positive test after offering free HAART treatment to all affected by HIV. Observational studies from British Columbia also reported a decrease in new HIV infections between 1995 and 1998 alongside expansion in HAART access (Montaner, 2006).

As a result, TasP has gained support from numerous international organisations such as the World Health Organization (WHO) and The Joint United Nations Programme on HIV/AIDS (UNAIDS). These observations led to the implementation of HIV treatment as prevention in British Columbia and paved the way for the inception of the *STOP HIV/AIDS* project in British Columbia.

STOP HIV/AIDS is a provincial initiative that was originally rolled out in 2010 and implemented in two health service delivery areas (HSDA), the Vancouver HSDA and the Northern Interior HSDA. The project expands HIV testing, treatment and support services for all British Columbians and is deployed through the various provincial health authorities (HA). The project was expanded to the rest of the province on November, 30th 2013 by the BC Ministry of

Health (Heath, 2014). The *STOP HIV/AIDS* project has been associated with a reduction in mortality, morbidity and HIV transmission (Montaner, 2014).

STOP HIV/AIDS implementation is supported by the Leadership Committee, which includes representation from health authorities, the Provincial Health Services Authority, the BC Centre for Excellence in HIV/AIDS, and representatives from the community. Each HA has a STOP HIV/AIDS team that implements the project in their respective Health Authorities and is overseen by the BC Ministry of Health. HA led teams, although slightly differ, primarily consist of epidemiologists, program managers, coordinators, medical health officers and regional managers.

The STOP HIV/AIDS project aims are (MOH, 2012):

Primary Aims

Aim 1: To enhance HIV case finding in BC

Aim 2: To increase the number of HIV-positive people accessing care

Aim 3: To increase the number of HIV-positive people on HAART, consistent with the 2008 Therapeutic Guidelines

Aim 4: To monitor HIV/AIDS related morbidity and mortality and HIV incidence in BC

Secondary Aims

Aim 5: To monitor drug adherence, resistance, and adverse events

Aim 6: To expand health care capacity to support HAART

Aim 7: To monitor population impact, resource utilization and cost-effectiveness associated with expansion of HAART access

Aim 8: To model the potential impacts of further HAART expansion in BC

Quarterly reports

The British Columbia Centre for Excellence in HIV/AIDS (BC-CfE) oversees the monitoring of the *STOP HIV/AIDS* program through province-wide and HA specific quarterly monitoring reports. These monitoring reports were developed to address the STOP HIV/AIDS goals, based on key indicators constructed through a collaborative process by a representatives from all five HA and to help inform future *STOP HIV/AIDS* planning (Lourenco, 2014). HA Goals of the project include: a reduction in the number of new HIV infections in BC; improvements in the quality, effectiveness, and reach of HIV prevention services; an increase in early diagnosis of HIV; a reduction in AIDS cases and HIV-related mortality (Lourenco, 2014).

The first STOP HIV/AIDS quarterly monitoring report was issued in the second quarter of 2013, making them available to end-users for about 3 years now. Quarterly reports provide up-to-date data on a variety of key HIV-related surveillance and treatment indicators. The report comprises of 4 sections that encompass a total of 13 indicators (See table 2). Selection of these indicators was achieved through a collaborative process with various Health Authority representatives. There are six reports in total, one for each HA and one for the province of BC as a whole. In addition, there is a technical report which explains how each HIV indicator is constructed (BC-CfE, 2014). Data used in these reports are obtained from several different sources. The British Columbia Centre for Disease Control (BCCDC) provides surveillance data on HIV, the BC-CfE provides data from the treatment registry and health administrative databases are obtained from the Ministry of Health (Nosyk, 2013). Additional data is retrieved from the provincial drug dispensation records and mortality records.

The objectives of the STOP quarterly monitoring reports are to:

1. Provide timely HA-specific information on key HIV indicators which will guide and inform HIV leaders and innovators in the development of future HIV interventions and programs which will ultimately lead to decreasing the burden of HIV in BC. The indicators will reflect ongoing or past successful public health interventions and highlight areas in the HIV care spectrum which require further attention and support.

2. Highlight limitations in our current data due to incomplete or time lagged data and to develop future strategies to improve complete and timely data capture

Defining Public Health surveillance systems

Public Health surveillance systems are a tool used in public health to estimate the health status, disease incidence and behaviours of populations (Nsubuga, 2006). The Centre for Disease Control in Atlanta defines public health as the ongoing systematic collection, analysis and interpretation of data that results in public health action (CDC, 2011). Alexander Langmuir, the first chief epidemiologist at the CDC is widely known as the founder of public health surveillance. In 1968, Langmuir and colleagues at the World Health Organization conducted the very first public health surveillance assembly (Thacker, 2012). This assembly set the foundation for public health and epidemiologic surveillance as we know today.

An important distinction to note about public health surveillance is that they branch off into two major types: active surveillance and passive surveillance. HIV infection and AIDS cases are typically reported through a combination of active and passive surveillance. Active surveillance is a system that employs staff to collect data regularly from health care service providers (Nsubuga, 2006). Active surveillance occurs when health departments or organisations proactively collect information about diseases. Although expensive and time-consuming, it provides the most accurate and timely information. An example of active HIV surveillance data is data collected through visits by staff members to clinics and hospitals to ensure accurate and timely data reporting.

In contrast, passive surveillance systems compiles notifications of diseases by relying on health care providers such as hospitals and clinics to regularly report (Nsubuga, 2006). Passive surveillance systems depend on compliance from health care providers and can lead to under-reporting of diseases. Although, passive surveillance system do not provide as timely or accurate information because of its reliance on external institutions to report data - it is cheaper to implement. An example of a passive surveillance system would be a surveillance system that involves the diagnosing doctor to provide information on date of testing, route of exposure, place of infection and the results of HIV tests voluntarily and regularly to health authorities. This information provided by the physicians would then be analyzed and included in a surveillance system.

HIV/AIDS surveillance has evolved over the years and has helped shaped our understanding and response to the epidemic. AIDS surveillance preceded HIV surveillance and initiated in 1981 by the CDC in the United States. For the next decade AIDS surveillance changed as the definition of AIDS evolved to include individuals with indicator diseases such as Kaposi Sarcoma and Pneumocystis (Valdiserri, 2000). These revisions to the definition of AIDS ultimately increased the usefulness of AIDS surveillance, as more cases were being diagnosed by physicians (Valdiserri, 2000). AIDS related morbidities and mortalities declined as advancement were made in HIV prevention and treatment (Gulick, 1997). Thus, in order to capture the effect of these interventions, AIDS surveillance alone was ineffective in the reporting of trends in HIV infection (CDC, 1996; Gulick, 1997).

It was not until 1997 that the CDC in the United States urged all states and territories to expand on their AIDS surveillance to include HIV surveillance as well (Gulick, 1997). Furthermore, HIV surveillance research done by the CDC found that 25 states reported decreases in AIDS incidence but did not find comparable reduces in newly diagnosed HIV

cases (Valdiserri, 2000). This effectively led to the broader use of HIV surveillance data as a prevention tool to create policies, monitor and control the HIV/AIDS epidemic.

The BC-CfE quarterly monitoring reports comprise of a combination of active and passive surveillance systems. Some of the data is passively collected through statistics Canada and vital statistics BC whereas, other data such as BC-CfE drug treatment program database is actively collected directly by the BC-CfE.

Role of surveillance systems as tools in public health

Historically, the best recognized uses of public health surveillance data are in the detection of disease epidemics and population health problems. Since its growing uptake in public health in 1968, surveillance systems have been estimating the magnitude of health problems and the geographic and demographic distribution of health issues (Thacker, 2012).

Public health surveillance systems enable governments and organizations to monitor and accurately describe the patterns of disease in a population and provide the data needed to guide interventions for populations. In addition, they support program planners in understanding the dynamics of epidemics among different populations in different settings (Pervilhac, 2005). Surveillance data are also used for advocacy (Pervilhac, 2005) and are crucial for tracking progress and informing resource allocation decisions while empowering decision makers to lead and manage more effectively (Innes, 1990; Jamison, 2006).

Evidence based decision-making is increasingly advocated for and used in public health (Taylor, 2010). Evidence-based decision-making consists of relevant, up-to date population data and evidence derived from scientific studies (Taylor, 2010). To help inform the decision-making process data on certain populations and their sub-groups is required, along with the prevalence of the problem and potential interventions. Surveillance systems provide the population level

data and evidence required to guide effective and meaningful decision-making by policy makers (Chu, 2012; Taylor, 2010). Thus, surveillance systems have been increasingly used and play a pivotal role in assessing initiatives and formulating new strategies in public health.

Although surveillance systems play a significant role in decision and policy making; a number of qualitative and survey-based studies suggest that data from surveillance systems may have limited role in informing public health decision-making. A study done evaluating a syndromic surveillance system in Ontario found its limited use in decision-making (Chu, 2102). Similarly, a study evaluating a national paediatric surveillance system reported that out of 15 public health professionals surveyed, only 3 reported using the surveillance reports to formulate and guide policy decisions (Gazarian, 1999). Likewise, a study done in Australia reported low use of reports for strategic planning and decision-making (Pope, 2005).

Another key role within the decision-making process is the role surveillance systems play in the prevention and monitoring of epidemics such as HIV/AIDS. Surveillance systems generate data that is required for monitoring and evaluating the impact of specific HIV interventions (Larmarange, 2015). In addition, HIV/AIDS effects diverse groups of individuals and surveillance helps identify which communities are affected the most, subsequently, tailoring treatment and prevention efforts to these communities.

Significance of performance indicators

Performance indicators in surveillance reports also play a pivotal role in monitoring and preventing disease incidence. The significance of performance indicators is well documented in the literature (Birch, 1986; Brownson, 2009; Freeman, 2002). Indicators provide a source of accountability and a source of formative quality improvement (Freeman, 2002). Furthermore, they provide visible and concrete proof of performance within a surveillance system (Freeman, 2002). The Declaration of Commitment on HIV/AIDS adopted at the UN by

189 member states in 2001 measured success in AIDS response by the achievement of concrete, time bound targets (UNAIDS, 2010), a practice that has continued with the latest targets, set out by UNAIDS, to diagnose 90% of those infected, treat 90% of those diagnosed, and ensure 90% viral suppression among those treated by 2020 (UNAIDS, 2014). Reaching the UN goals entails the careful monitoring of progress in the specific indicators used in HIV/AIDS surveillance. Effective HIV/AIDS indicators enables surveillance systems to evaluate the effectiveness of their policies and programs.

Evaluation of surveillance systems

Ensuring public health surveillance systems are efficient and effective is increasingly recognized as critical to improving health conditions across all disease areas. Evaluation of surveillance system is a method to ensure that resources are being used effectively and ensures issues of public health importance are monitored effectively (CDC, 2001; Drewe, 2012). Evaluation of surveillance systems also plays an essential role in maintaining trust and credibility from all authorities involved in the project or funding the initiative (Drewe, 2012).

A surveillance system is considered useful if it generates a public health intervention that reduces the negative health effects (CDC, 2001). A report issued by the CDC on guidelines for evaluating surveillance systems states that surveillance systems, although uniquely different in methodology and objectives, should all be evaluated periodically to promote the best use of public health resources (CDC, 2001). Evaluations assess if surveillance systems serve as a useful public health tool and more importantly, if they are meeting the systems objectives (CDC, 2001).

The literature on evaluations of surveillance systems is divided in two groups: studies assessing the usefulness and uptake of reports and studies conducting formal evaluations on an array of different attributes of surveillance systems (Calba, 2015; CDC, 2001; Drewe, 2012).

Assessing the usefulness of surveillance systems is deployed through qualitative and quantitative methods, in the form of survey and in-depth of interviews. A study assessing the usefulness of STI surveillance data in Australia used a survey to assess the readership and uptake of reports while conducting interviews to assess how useful the reports were and how they informed policy changes. Similarly, Pega at al. explored the extent and ways in which the reports were used by administering surveys and conducting interviews (Pega, 2013).

The literature showed mixed results on the uptake of surveillance reports among intended end-users. Numerous studies found surveillance reports to have low uptake and readership while other studies found reports to be used extensively (Grenier, 2004; He, 2009 Knowles, 2012, Pega, 2013; Pope, 2005). A study evaluating the use of a British Paediatric surveillance system and their effect on policy through questionnaires found reports were used extensively by UK paediatricians (Knowles, 2012). However, a similar study found that only 49% of end-users reported that they used the surveillance reports (Pope, 2005). Similarly, another study reported that end-users of surveillance reports found indicators or reports in general to be hard to interpret and thus seldom used (Pope, 2005). Despite, conflicting results of report use those in positions of authority such as Medical Health Officers and Directors had a tendency to use the reports less (Pope, 2005).

The literature on the usefulness of reports strongly show that surveillance reports were useful and valuable to end-users (Pope, 2005; Grenier, 2004; Knowles, 2012). Studies consistently found end-users to be satisfied with the overall content and quality of reports (Grenier, 2004; Pope, 2005; Pega, 2013,). However, end-users of the surveillance reports stated different reasons as to why they found the report valuable and useful. Grenier et al., reported 70% of participants used the report as guide to inform immediate action while 40% used the reports as the basis for future research (Grenier, 2004). Other studies reported the

surveillance reports were used for reference purposes, gaining knowledge on disease trends and evaluating public health policy (Grenier, 2004; Pega, 2013).

Lack of evaluation has been argued to hinder the development of data and surveillance systems and prevent maximizing the utility of surveillance reports (Sandiford, 1992). Furthermore, regular and relevant evaluations of surveillance systems are crucial to the improvement of performance and efficiency. Evaluations of surveillance reports should conclude with recommendations for improving quality, efficiency, usability and usefulness (CDC, 2001). Above all, evaluations should focus on how well a surveillance system is meeting its own objectives.

Currently, there are different methods of evaluating surveillance system constructed by the CDC and WHO that cover many different attributes of surveillance. Evaluations of surveillance system based on these aforementioned guidelines do exist and are more commonly practised and are predominately tailored towards active surveillance systems. The methodology deployed by this study uses many of the attributes recommended by the CDC and WHO but differs because our surveillance system is not just an active surveillance systems but a combination of both passive and active systems. In addition, our study serves as a preliminary exploration of the perceived usefulness and uptake of quarterly monitoring reports among report users, with the ultimate goal to identify areas for improvement. The literature on the evaluation of surveillance systems is divided into two categories: in-depth evaluations on the specificity, simplicity, flexibility, sensitivity and predictive value positive and evaluations that aim to determine the usefulness, uptake and role in decision-making of the surveillance reports (Banks, 2001; Bingle, 2005; Gazarian,1999; Pega, 2013; Pope, 2005). Studies differ because surveillance systems objectives vary and thus emphasizes certain attributes more than others. For the purpose of this capstone this paper will prioritise usefulness, simplicity and uptake attributes for our evaluation.

Study Goals

While the role monitoring and surveillance systems play in improving health outcomes is well documented (German, 2001; Innes, 1990; Larmarange, 2015; Segone, 2008), the use of *STOP HIV/AIDS* quarterly reports and more specifically, their impact on policy has not yet been evaluated. The study aims to explore and understand the use of quarterly reports by representatives of the Health Authorities on the STOP project. The main goal of this study is to improve our understanding of the uptake of monitoring reports by Health Authorities and their use of indicators to improve the quality of HIV care in British Columbia. In particular, the study will investigate the extent to which monitoring reports guide and inform future interventions and policy decisions for decision-makers. The findings from this study can determine if developments to the monitoring reports and indicators would be valuable.

Objectives of study

This study seeks to understand how monitoring reports and their indicators are used by HA end-users, and their role in informing policy decisions as quality improvement tools. The research questions are:

1. What are the HA-led team members' perspectives on the usefulness of quarterly monitoring reports? For the purposes of this study, usefulness is defined as the extent to which an information system provides benefits or value to end-users.

2. What do Health Authority-led teams understand to be the *purpose/goal* of the quarterly monitoring reports?

3. What role do the quarterly reports play in policy and programmatic decision-making within the Health Authorities?

4. What are the Health Authority-led teams' perspectives on the significance of specific sections and indicators to their operations?

- Which indicators are considered most significant towards quality improvement work?
- Which indicators are difficult to interpret?
- How could sections and indicators be presented differently to better meet needs of health authorities?

5. How could the quarterly monitoring reports be improved to better meet end-user needs?

Methodology

Research Design

The study was a mixed methods design that employed a survey questionnaire as well as in-depth interviews with key informants. This allowed us to both assess the uptake of the reports while also gaining an in-depth understanding of perceived usefulness of the reports and identifying possible recommendations to enhance the quarterly reports.

The email administered survey was developed through a collaborative process with three other members of the study team, including the director of the STOP HIV/AIDS Program at the BC-CfE, a senior health economist who works with STOP HIV/AIDS data, and a qualitative health researcher. Some questions on the survey were adapted using the CDC Updated Guidelines for Evaluating Public Health Surveillance Systems (German, 2001). The survey questionnaire assessed the usefulness and impact of quarterly monitoring reports while also examining the intensity of use and uptake of monitoring reports at the various health authorities that are involved in the STOP HIV/AIDS project. After a few revisions, the survey was limited to a total of 14 questions. Surveys were administered online through *Fluid Survey*

and disseminated electronically through email. Two follow up reminder emails were sent to non-responders.

The next step was the key-informant interviews that aimed to assess the perceived usefulness of the monitoring reports and indicators to HA end-users, and their subsequent influence on the decision-making process. The in-depth interview guide was developed through a collaborative process with all involved in the study and adapting the questions and formats of interview plans recommended in the Guide to Organizing Semi-structured Interviews with Key Informants: Safety Diagnosis Tool Kit for Local Communities (Laforest, 2012). After multiple revisions and a pre-test of the interview, a semi-structured interview consisting of 6 sections was finalized.

Sampling and Recruitment

The study surveyed members from two committees involved on the STOP HIV/AIDS project, the Technical Monitoring Committee (TMC) and the Collaborative Implementation Committee (CIC). Members were representatives of their respective HA and consisted of Medical Health Officers, Epidemiologists, Regional Managers and Directors of Prevention Services and Project Coordinators (See table 1). Key-informants from these two committees were selected for recruitment from this pool by the Chair of the STOP HIV/AIDS technical monitoring committee, who is also the Assistant Director at the BC-CfE and Senior Medical Director at Vancouver Coastal Health, along with the Director of Operations at the BC-CfE. Four members were selected through snowball sampling by pre-selected participants who were either not available or felt their involvement with the quarterly reports were limited. All participants that were identified by chair of the STOP HIV/AIDS and director of operations were included in the study. Participants were sent initial invitation emails to participate in the study. After a week, one follow-up invitation was sent to non-responders. A total of 13 interviews were

conducted and were all one-on-one interviews except for one that was conducted with two participants concurrently.

Interview Guide

We chose to conduct in-depth interviews to gain a deep understanding of the use of quarterly monitoring reports. The interview guide was established through multiple drafts and revisions before being finalized (See Appendix B). Although a survey was also deployed, qualitative methods such as interviews are more informative and useful for capturing the experiences of participants (Steinar, 1996). Conducting interviews will assist in producing reliable and in-depth qualitative data while also allowing for the opportunity to identify new questions that may emerge through the use of open-ended questions (Bourgeault, 2010; Turner, 2010). Semi-structured interviews will allow us to retain the flexibility of qualitative research while also allowing for greater standardization (Bourgeault, 2010).

The literature indicates that qualitative methods are highly effective when conducting outcome evaluation (Steinar, 1996). Interviews allow participants to discuss their needs and thoughts without being restricted to a pre-selected categories. The interview guide comprised questions assessing: the usefulness of the reports by end users, end users perceptions of the usefulness of the reports, the purpose or role of the quarterly reports, their role in decision-making and the significance of the various performance indicators.

The project used quantitative methods in the form of a survey questionnaire administered through the web. Surveys allowed us to collect the same set of data from all participants and quantify the usefulness of the reports to end-users. Survey questionnaire collected similar data as the qualitative interviews however, focused more on the uptake and specific questions on the usefulness of the reports (See appendix A).

Procedure

Interviews were conducted form July 17th to August 7th, 2015. The majority of the interviews were conducted at each health authority the participants were working for, with the exception of three individuals who requested to be interviewed at the BC-CfE. All interviews were conducted in private rooms. Interviews ranged from 25 to 55 minutes.

Data Analysis

Each of the interviews was audio taped and transcribed. Thematic data analysis was conducted to analyze the interview data to assess the use and the impact of the reports on the STOP HIV/AIDS projects work by the HA's in the province. Green and Thorogood's (2009) approach and guidelines was applied for thematic analysis. A thematic analysis approach was selected due to its usefulness in answering the most salient issues in a research project (Green, 2004). It emphasizes the examining and pinpointing of data to identify implicit and explicit themes found in the data rather than simply counting phrases or words in a text (Green, 2004). Interviews were reviewed, coded and analyzed by one researcher. Thematic analyses was conducted by reading transcriptions several times, producing initial open codes, generating themes by collating codes, reviewing and refining themes and generating the final report. Themes were separated into parent themes that matched the original research objective inspired themes, and subsequently sub-themes were identified.

Findings

Findings from the survey and qualitative interviews are presented separately in two sections.

Survey Results

HA-led team members' perspectives on the usefulness of quarterly monitoring reports

Survey results indicated that many of the key informants do not review the reports regularly. 63% of respondents stated that they ‘always read’ the report, compared to 27% who reported they ‘sometimes read’ the reports. When asked how often they read the reports each quarter, the majority (45%) stated less than an hour; while 27% responded 1-2 hours and 3-5 hours, respectively. In addition, 45% of respondents reported that they held meetings to discuss the reports once a quarter, while 27% stated that they held meetings ‘less often than quarterly’. This could in part be explained by the low scoring of the ‘ease of reading and navigating’ through the reports. 54% of respondents scored the ‘easiness of reading navigating’ through the reports from 4-7, where 10 is “very easy”.

Purpose of the Quarterly Monitoring Reports and the role they play in policy and decision-making

When asked how they use the report, 81% responded for planning and implementing public health initiatives, another 81% stated they use the reports to evaluate public health initiatives. In contrast, only 45% used the reports to inform the development of policy decisions.

Significance of specific indicators

Overall, the informants were comfortable with the indicators included in the report and the quality of the indicators. When asked how well end-users understand the indicators, 63% of respondents scaled the results between 8-10, (10= completely understand and 0= do not understand). 45% of respondents rated the relevance of indicators to their work between 8-10, where 10 is “very relevant”. When asked if end-users of the reports have ever asked for and needed clarification of the data in the report, 63% responded “no”.

Finally, when respondents were asked what their preferred format to access the report, 54% of respondents indicated they would prefer to change the format while 36% stated that they

preferred to keep the current format. Of the respondents that preferred a new format, 45% selected an interactive web-based tool.

Qualitative Results

HA-led team members' perspectives on the usefulness of quarterly monitoring reports and purpose of the Quarterly Monitoring Reports to users

Comparability of reports

Producing HA specific reports every quarter was described as very beneficial to each HA. All participants stated that they preferred HA specific reports over just having a province wide report, as it allowed them to compare their progress to other HAs. One interviewee indicated that they "…see [the reports] as a way for them to look at how all the health authorities are doing in relation to the mandate we have been given from the ministry".

In addition, interviewees stated that having the ability to compare results also allowed them to see where certain HA are doing well. This in turn would lead to adopting policy or interventions that worked for certain HA and implement them at their respective HA. As one participant stated,

"…to have a graph of figures that have all of the health authorities on there and shows side by side or maybe even the same graph so that you can say "oh my god look at Island health and the wonderful job they are doing and getting people who are more active on therapy. We can then contact them and ask what they are doing and how are you doing it and then we can share methodology and intervention." Interviewee 2 - Epidemiologist

Reports as a way to "help reach goals"

Many participants, when asked how the quarterly monitoring reports aided in their work towards reaching the STOP goals, indicated that it allowed them to assess their progress towards the goals every quarter. Interview participants stated that the quarterly reports enables them to see how their activities or the STOP program in general are positively effecting the HIV/AIDS status in their regions. One participant stated,

> *"The purpose is to help people reflect on the impacts of their activities and adjust those activities in a way that is data informed and try to constantly do better to meet the targets of the program". Interviewee 4 – STOP coordinator*

Interviewees acknowledged that without the report it would be difficult to evaluate their work. As one client stated, "We definitely are using it to evaluate, we are keeping our eyes very closely on the numbers and as we roll programs and as we change programs we do look at these reports to see if there are any differences in the numbers we are seeing".

Furthermore, many participants specified that the reports allow them to provide updates on testing rates and HIV/AIDS incidence rates to their HA, media and community organizations. One participant stated that they used the reports "to share updates on our progress of testing and treatment and engagement in care".

Quarterly Monitoring Reports role in policy and decision-making

Emerging role of reports in decision-making

One of the main objectives of this study was to understand how the reports informed policy decisions. All participants noted that the quarterly reports informed their decision-making process. However, many participants could not give specific examples of how quarterly reports had informed specific policy or programmatic decisions. One participant stated, "We are still in the active roll out of the STOP HIV, we are definitely not at the sitting back and waiting back for the fruits to be sowed. We are still trying to plan and roll out…". Some participants stated that

the reports helped them target priority populations that were identified in the report. Many participants said they constantly used the reports to evaluate their progress. However, participants did acknowledge the benefit of using the reports for strategic planning in the future.

The significance of specific indicators

Some indicators difficult to interpret

Overall, most participants liked the majority of indicators and found them to be very helpful to their work. Interviewees described using the testing indicators the most, followed by the new HIV diagnoses indicator, the stage of HIV infection and the cascade of care. Participants also stated they were comfortable interpreting the indicators. However, some participants found some of the indicators either difficult to interpret or not helpful towards their work. Almost all participants stated the indicators they found to be not helpful or that they did not refer to quarterly were the HIV mortality and AIDS defining illness solely due to the very small numbers of deaths; instead they viewed these indicators on an annual basis. Many participants said they did not use the PCS score indicator because they found it hard to interpret. Of the interviewees that used the PCS score, only one participant, a clinician, indicated that they used it often.

Cascade of Care metrics may not be capturing adherence sufficiently

The cascade of care was another indicator that received mixed views from participants. The majority of interviewees used the cascade of care and referred to it often, stating it enabled them to see the number of individuals not linked to care and ultimately virologically supressed. However, a few participants stated that the definitions of the cascades needed to be explained better in order to fully understand each stage of the cascade of care. In particular, some participants did not agree with the adherence definition and felt that the definition should be changed to individuals who are fully adherent to treatment and not individuals who only pick up

medications, as they may not be fully adherent. They stated they had issues with the drop off between number of individuals who were adherent and individuals suppressed. As one participant stated,

"…we have plenty of discussion about the definitions of the measures for adherence. Because I think it's defined as people who pick up their medications on a regular basis. Which doesn't necessarily mean they are taking it. So, and we often see that it is relatively high in adherence but the suppression levels are low and it really should be almost the same if we were really measuring adherence well." Interviewee 5 – Medical Health Officer

Current stratification is sufficient

When asked about the stratifications of the indicators, participants all stated that further stratifications were not needed and the current stratifications of gender, age, and exposure category were sufficient. Many participants stated that if any further stratifications were needed that each HA would take it upon themselves to create them.

Areas for improvement

The themes compiled in this section describe the limitations and barriers of the quarterly monitoring reports. Participants identified limitations that reduced the uptake of the reports that could be improved upon. In this section, I will explain the limitations and the suggestions participants offered to improve the reports. Finally, I will conclude with additional areas of improvement that could increase the uptake and utility of the reports

More accessible format of the report

Although participants appreciated that the data was compiled for them by the BC-CfE and saved them a lot of time, a number of participants identified the format of the report as a barrier that limited use of the reports. The quarterly reports are currently in the form of a PDF

document that is sent to all STOP members and is accessible online on the STOP website as well. Participants noted that the PDF format does not allow them to extract certain data, graphs or tables that were significant to their work. One participant stated, “We have never been able to get that data in terms of a usable file where you can actually extract information. They have only ever sent us it as a PDF”.

Although, some participants stated they were still able to extract the data they needed but could only do so through tedious methods such as cropping and pasting. It was noted by one of participants as: “A pdf you have to download and then take a snapshot and then cut and paste. But often when you go to expand it, it’s not as clear. So yes, it is a problem but not all the time”. Extracting data through this method was possible but was an inconvenience that could be addressed.

Participants suggested to change the format of the report to a more accessible and extractable form such as an excel file. Excel files would enable participants to extract the data they need faster and with better quality.

Reports are quite lengthy

Many participants identified the overall length of the reports as a barrier as well. Participants stated that they would only look for the data they needed and either briefly skim the report and/or ignore all other sections of the report. They stated the impediments to reading through the report in its entirety was mainly due to its length. As one participant noted,

“…what they [members of the STOP project] won’t do is go through a 25 page [quarterly report] and extract the information that they need from it and then kind of sort through what variables and what tables and figures are appropriate”. Interviewee 3 - Epidemiologist

Another participant echoed these comments and said, “The one thing about it is every quarter you have to go through it [quarterly report] and you have to look at every section”.

Despite, the concern with the length of report participants did not advocate to reduce the report or omit any of the indicators. They acknowledged the importance of all indicators but did not like the length of reports.

Succinct high level summary would be helpful

As a suggestion to increasing the uptake of the reports, participants stated they would like to receive a succinct high level summary with key highlights sent alongside the quarterly reports. By providing this summary page with the quarterly reports, end users would not miss any significant information. One participants described what the summary page would consist of as: "…it doesn't have to be long, it doesn't have to be several pages just a one pager with high level summary that kind of tell you what's happening".

Another participant noted, "What they need is a targeted one pager that goes out to them that they can hold that says testing rates by LHA and then some draft that shows them the testing rates for LHA. They could just quickly look and then move on".

Additional data

A contradiction arose between the length of the report and the inclusion of more data. Participants previously noted that the length of the report was a barrier that reduced the utility of the report. However, the same participants also indicated they would support adding more data into the reports. The themes below that supported the addition of new data include the granularity of data, inclusion of harm reduction and STBBI data and knowledge translation.

Granularity of data

Most clients interviewed stated that BC-CfE could add more granular data – local health area (LHA) - as opposed to just health service delivery areas. Participants from the Health Authorities that covered larger geographical areas were the most vocal about adding LHA level data. They found that HSDA level data were too broad to use. One participant noted that

although LHA level would be nice they felt it was the responsibility of the health authority to break down data into more granular data.

Inclusion of harm reduction data

End-users of the report indicated that they would also like to see harm reduction data and Sexually Transmitted and Blood-borne Infection (STBBI) data incorporated into the quarterly reports. Participants indicated that incorporating harm reduction data such as needle and condom distribution would be helpful in identifying patterns and trends in HIV diagnoses. As two participants stated:

> *"The harm reduction side is such a key part of HIV prevention and should maybe go on the reports." Interviewee3 - Epidemiologist*

> *"there isn't any data spit out around harm reduction work. I don't know if that will change anytime soon. That's something that could be all integrated into one report" Interviewee 7 – Medical Health Officer*

Although the epidemiologist advocated the most for the inclusion of harm reduction data and STBBI data, at least two other end-users that were interviewed shared this view as well.

More knowledge translation needed

Another area that was identified by participants that could improve the use of the quarterly reports was adding more knowledge translation – interpretation and breakdown of indicators. Although brief descriptions of each indicator and graph are provided in the reports, participants indicated that some of the graphs and indicators were difficult to interpret and suggested more knowledge translation of indicators. Participants felt that more knowledge translation would improve their understanding of the reports and subsequently, increase the uptake of the reports. One participants described the need for more knowledge translation as:

> *"I think what's missing between the monitoring reports versus what's in the hope to health is some of those context pieces. What does this mean or what is past just the pure stats and what's is happening and what does that mean in that context or what you are doing." Interviewee 4 – STOP HIV/AIDS coordinator*

Another participant acknowledged the technical reports but stated having some explanations accompanying the indicators would be helpful for most end-users, as some might not know the technical reports exist. Some participants that wanted more knowledge translation were advocating for front-line workers who might use the reports. One participant noted that by having more knowledge translation attached to the indicators, the uptake of the reports would increase amongst frontline workers.

Although these explanations are also suggested to be included in the succinct high level summary, participants did not want a breakdown of every indicator in the summary but only the key indicators and significant changes to be included in the summary piece.

Discussion

The results from the study showed that end-users from the HA's used the quarterly reports for evaluating progress, attaining provincial goals and comparing across HA. Reports were not disseminated actively nor were meetings held frequently within HA to discuss results from the quarterly reports. Respondents also reported that the quarterly reports enabled them to assess the progress of the project and towards reducing HIV/AIDS burden. The indicators in the reports were found useful and valuable to work done by the HA-led STOP teams with the exception of a few respondents that felt like they were difficult to interpret, use, or not significant to their work. Overall, the study showed that the quarterly monitoring reports could be improved by providing: succinct one or two page documents highlighting key changes; changing the format of the report

to a more accessible format; including more granular data and simplification of data for frontline staff.

Although our results are encouraging, they indicate areas of possible improvement to increase the uptake of reports. Our findings show that the participants could not describe specific applications of the quarterly monitoring reports for strategic planning and decision-making, despite participants responding in the survey that reports were used for planning public health initiatives. Although they did not report using the reports for policy making, participants did acknowledge the perceived role the reports would play. These results were consistent with those found in the literature (Banks, 2001; Pega, 2013; Pope, 2005). A study conducted in the US found a quarter of policy makers didn't examine state surveillance systems despite recognizing the usefulness of the surveillance reports (Pope, 2005). Similar studies reported end-users seldom use of the reports to inform strategic planning and decision-making (Pega, 2013).

Our study found various different usages for the quarterly monitoring reports. Participants stated the reports were useful in measuring progress, reaching goals, reducing HIV/AIDS burden and assessing trends in HIV/AIDS. The uses of the reports were consistent with the literature (Banks, 2001; Bingle, 2005; Pega, 2013; Pope, 2005). Studies reported using the reports mainly for accessing information and trends (Banks, 2001; Pega, 2013).

Another interesting usage of the reports that is not found in the literature is how participants used the reports to compare how their respective HA was doing in relation to the other HA's. Furthermore, some participants noted they might use the reports information to adopt policies or interventions from HA's who are doing significantly well in certain areas of the STOP project. This was notable because 'comparability' was not one of the objectives of the quarterly monitoring reports. Also, this may have negative implications given the difference amongst HA

in size and target populations, making it difficult to draw any valuable findings through comparisons of the aggregate data alone.

Survey results from our study found that 45% of respondents read the report for ‘less than an hour’ and 27% said they spend ‘1-2 hours’ per quarter reading the report. Although our core focus was not to capture the readership of the reports, these number gave us a glimpse into the uptake of the reports among a diverse group of end-users. The findings of the qualitative interviews suggest that report uptake and use could be limited by the format and length of the report. The quarterly monitoring reports are quite long, and consist of 36 pages with 16 figures and 14 tables, and a total of 13 performance indicators. The length of reports were also identified as barriers to readership and uptake of reports in the literature (Banks, 2001; Pope, 2005). Participants stated reports uptake would increase if a summary page was attached to it. A similar study done in Australia also found end-users who found the reports to be dense and cumbersome advocated for a summary article (Pope, 2005). Including a high level summary page could increase the uptake and understanding of the reports.

Additional indicators

Participants were comfortable with most of the indicators and did not face many difficulties interpreting the data in the indicators with the exception of a few. There were a couple indicators that participants identified as not being a significant to their work. Participants suggested providing more definitions and explanations for some of the indicators such as the cascade of care and the programmatic compliance score. Overall, the indicators were identified as significant to the work of the health authorities.

Participants did also suggest including more indicators. Mainly, the inclusion and integration of other sexual transmitted infections (STI), hepatitis and other blood borne diseases. Literature on integrated surveillance systems show that integrating behavioural,

hepatitis and STI data with HIV surveillance is critical to understanding the biological and behavioural dynamics and could also serve as a proxy measure to the effectiveness of HIV prevention programmes (Defraye, 2011; Rehle, 2004; Mills, 2004). In the late 1990's, UNAIDS and the WHO introduced second generation surveillance to supplement HIV surveillance. Second generation surveillance includes assessing behavioural and STI data trends to further understand which behavioural changes are responsible for HIV as well as blood borne infections (Zaba, 2005). PLWHA are not only susceptible to HIV but can also face threats from other disease. MSM and IDU communities can also face higher risk of STI and hepatitis due to similar transmission routes (Dowell, 2009). Furthermore, co-infection of HIV and STBBI has been shown to alter treatment recommendation due to changes in the clinical course of disease (Dowell, 2009; Rehle, 2004). Studies advocating for the integration of HIV, STBBI and Tuberculosis base this on the mounting epidemiological and biological evidence that have pinpointed the cofactor role STI's play in facilitating HIV transmission (Rehle, 2004). A study that integrated surveillance systems reported that HIV care providers were alerted to a rise in HIV and syphilis co-infection which led to more interventions to prevent transmission (Dowell, 2009). However, challenges and barriers do exist and include incompatible databases, time lag on reporting of STBBI/HIV data and the length of time to integrate and lack of expertise (Dowell, 2009). Harmonizing HIV and STBBI surveillance enables policy makers to implement effective prevention strategies and only strengthen and improve existing surveillance system (Dowell, 2009; Sweeney, 2013)

Respondents also asked for the addition of harm reduction's data such as condom and needle use and distribution and other safe injection supplies in the monitoring reports. Harm reduction's role in reducing the HIV epidemic is well documented (Ball, 2007; Zambrana, 2003). Harm reduction data enables decision-makers to create policies and interventions that can target drug users specifically and further strengthen the existing programs (Zambrana, 2003).

Current harm reduction data is compiled by the BCCDC Communicable Disease Prevention and Control Services by Health Authority. The literature on advocating for the integration of harm reduction data as it applies to HIV surveillance is sparse. However, given the evidence of effectiveness for harm reduction data, including harm reduction data could increase the effectiveness of surveillance data and help account for social and cultural factors that affect HIV transmission.

Respondents also felt that the inclusion of granular data would help assist in identifying target areas within their respective HA regions. The literature shows that the inclusion of small area geographic data can improve surveillance systems by better locating epidemics, targeting populations needs and provide insights into the service use of rural populations (Pope, 2005). Furthermore, it would improve the understanding of trends and provide insights into the patterns of more rural areas (Pope, 2005). However, providing more granular data poses an ethical issue because it could easily identify PLWHA. A study done in Australia reported that granular data could be produced while also making it difficult to disaggregate the data through methods such as standardization and combining several years of data (Pope, 2005).

Desired format for reports

The format of the report was also identified to be a barrier in uptake of the reports. The PDF format of the report makes it difficult to extract data or graphs directly form the report. Participants often use the data and graphs from the report to include in their presentations or disseminate within their respective HA or affiliated community organizations. Participants also noted that an easier format to navigate through reports would be helpful. Participants reported that an interactive web-based tool that allows them to compare outcomes over time more easily would help identify effective interventions. The literature on the use of interactive web-based tools is scarce. However, the UN data development group found that disseminating data through more user-friendly platforms ensures greater use and understanding of the reports

(UNICEF, 2010). Customized interactive web based surveillance reports would enable end-users to compare trends, extract and manipulate data with greater ease.

When analyzing the data on length of the report a contradiction arose between asking for more detail and brevity. Almost all respondents reported the reports were too long. Despite finding the report lengthy, some respondents also stated they would like more data to be included into the report. The data requested included: more granular data, linking STBBI data and harm reduction data, and more descriptions on the construction of some of the indicators. This paradox in the length of data begs the question if there is an issue with the way the reports are communicated to end-users. An interactive web-based tool could include the additional data end-users requested while also providing a different format that does not make the report seem as lengthy or cumbersome.

Research Limitations

The study had a few limitations and possible biases that could have altered the results of the study. Due to the nature of the study and timing (summer) there were a smaller number of participants and thus results are less generalizable. The study sample was small but was appropriate given the small size of our target population of HA end-users. Also, our study included member of the HA's with various different titles, with both senior and junior level members - representing a wide variety of users. We chose not to target frontline workers due to their limited engagement with the reports and because we were targeting HA members who were in a position to influence decision-making.

Response bias in the form of overstatement bias may have also been present in the study. Key informants may have given more positive feedback due to the fact the interviewer was representing the BC-CfE - the centre responsible for compiling and sharing the quarterly reports. An external interviewer may have received different feedback. For example, participants

may have had lower uptake of reports in practice, but may have given better answers to present themselves in a more favourable light. Therefore, it is possible that respondents over-estimated their uptake and use of the reports in our study because of moderator presence bias – respondents interpreting what they believe the interviewer wants to hear.

In addition, purposive sampling might have reduced the representativeness of the participants and subsequently, affected the results from this study. Participants in the study were not randomly selected but were selected through purposive sampling and snow-ball sampling techniques. Furthermore, of the initial group of participants identified, it is likely that individuals who responded and volunteered to be in the study might have had more engagement with the quarterly monitoring reports. Thus, our results could have had different findings from members who might not have volunteered to be in the study due to their limited engagement in the report.

Another limitation was some of the participants selected for the study were only on the *STOP HIV/AIDS* project for a short time, the shortest length of time being 7 months and the longest since the projects inception. Participants who were on STOP initiative for a short time may not have been able to provide detailed information on how the reports have guided and informed decision-making.

We would also like to acknlowdged that PLWHA, although at high-risk could also be part of a community that is underserved or marginalized. PLWHA are already subject to the stigmas and discrimination brought about by their illness, however, if they are already from a marginalized community this stigma is only further perpetuated and exacerbated. Our study did not focus on the community or patient level and thus, did not have a health equity approach. However, this could have limited the inclusiveness of the surveillance reports and its ability to capture these nuances amongst communities.

Future Research

This study illuminated many uses and benefits of the report as well as areas for improvement. Future research is needed to evaluating different attributes that are critical in improving surveillance systems. WHO and CDC recommend evaluating attributes such as timeliness, specificity, reliability, acceptability, sensitivity, predictive value positive, representativeness and stability of surveillance systems (German, 2001). Delving into these attributes could reveal more about the impact of the performance indicators, their quality and efficiency.

Studies focusing on the readership of the report might also prove valuable. This would provide quantified data on the use and readership that could explain why reports might not be used for strategic planning. Also, it could provide insight into how different end users might engage with the reports and if being a senior member and junior member might affect the use of reports.

Future research could also evaluate the impact and significance of applying a health equity lens to the surveillance report. Possibly adding some indicators that would provide a more holistic data collection that is representative of all populations affected by HIV/AIDS. Surveillance of equity related health outcomes and social determinants of health is highly significant (Marmot et al, 2008) and would inform programs and policies that would ultimately improve the HIV/AIDS care in BC.

Future studies could also include more participants in both the survey and the in-depth interviews, while also expanding participants to include front-line workers and community NGO's. Additionally, interviewing more STOP HIV/AIDS program managers and coordinators from each health authority may reveal more information.

Conclusion

The study has shown how there is a need for some improvements to the quarterly reports. The current reports are used for various different purposes such as guiding policy making and evaluating progress as reported by key-informants. The length of the reports coupled with the current format of the report are major factors in the uptake of these reports. Providing succinct summaries of the reports and changing the format could improve the uptake of the reports and their role in informing decision-making. Further work evaluating the different attributes along with the readership and adopting the WHO guidelines on the evaluation of surveillance data could provide valuable information on the efficiency and quality of reports; subsequently, providing additional novel ways of increasing uptake and the impact of the quarterly monitoring reports.

Critical Reflection

The study allowed me to gain invaluable experience conducting research and working with a renowned HIV/AIDS research centre, but it also provided me with many lessons learned. It gave me the opportunity to apply both qualitative and quantitative research methods which were highly beneficial. Constant collaboration and guidance from my preceptors helped enhanced the rigour of the methodology of the study. However, as my first study there are many areas that I could improve on that would have increased the rigour and efficiency of the study. Although I improved my interviewing skills throughout the course of the study, I think I could have still improved on probing interviewees when themes emerged that were outside of the research objectives. This did negatively affect my ability to analyze, understand and report on these emerging themes. Similarly, interviewees who gave shorter, less detailed answers for some question or were less open to discussing certain questions could have been improved by more consistent probing.

One lesson I leant is that it would have been helpful to be more reflective while conducting the qualitative interviews and thematic analysis. Possible biases on my end could have been identified through better note keeping throughout the data collection and data analysis stages. My literature review skills were also significantly improved as a result of this study. I was able see the significance of continuously re-visiting the literature and how this could have better informed my research protocol. Lastly, I have gained a thorough understanding of the many steps and processes involved in conducting research from inception to completion Overall, I developed many essential research skills while also gaining invaluable experience of the research process that I can build on in the future.

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Appendices

Appendix A – Survey Questions

Thank you for agreeing to participate in this survey measuring the use of monitoring reports as well as the usefulness of the reports to your organization. Given your involvement in the STOP HIV/AIDS/Hope to Health project we would like to ask you the following questions about the quarterly monitoring reports and how you use them.

The quarterly monitoring reports were introduced two years ago to evaluate the project and identify future interventions. Obtaining feedback from everyone involved on the project is vital to improving the reports, and ultimately the quality of care for people living with HIV/AIDS across the province.

The survey should take no more than 10 minutes to complete. Your responses are voluntary and will be kept confidential; analyses will use summarized, de-identified data.

1. What is your role/position on the STOP HIV/AIDS project?

2. How familiar are you with the goals of the *STOP HIV/AIDS (Hope to Health)* project?

- Very Familiar
- Somewhat Familiar
- Not familiar

3. How often do you consult and review the quarterly monitoring report each quarter?

- Always Read
- Sometimes
- Never Read

4. What do you use the reports for?

- For planning or implementing public health initiatives
- To inform the development of policy
- To evaluate public health practices
- Other *(Please Specify)*

5. How many hours do you spend reading and working with the new quarterly monitoring report every quarter?

- Less than 1
- 1-2
- 3-5
- More than 5 hours

6. Do you hold a regular meeting to discuss the results of the quarterly monitoring reports as a team?

- Yes

- No

7. How often do you hold a meeting to discuss the results?

- Less than bi-weekly
- Bi-weekly
- Monthly
- Quarterly
- Other (*Please specify)*

8. On a scale of 1-10 with 10 being “very useful”, how useful are quarterly monitoring reports to your organization?

- Not useful -1 ------ Very useful - 10

9. On a scale of 1-10 with 10 being “very useful”, how would you rate the quarterly monitoring reports usefulness as a quality improvement tool?

- Not useful -1 ---- Very useful - 10

10. On a scale from 1-10, with 10 being “very relevant”, how would you rate the relevance of the indicators to your work?

11. Do you think the quarterly monitoring report is missing any information that would be valuable to you?

- Yes
- No

12. If so, what do you think is missing?

13. On a scale of 1-10 with 10 being “very easy” how would you rate the ease of reading and navigating through the quarterly monitoring reports?

Very hard – 1 ----- Very easy - 10

14. On a scale of 1-10 with 10 being "completely understand", how would you rate your understanding of what the indicators are measuring?

- Don’t understand at all – 1 ----- Understand very well- 10

15. Have you ever asked for clarification or additional data to be included in the quarterly monitoring report?

- Yes
- No

16. If so, was this clarification useful, in that it sufficiently answered your question to the extent that you were able to carry out your intended task pertaining to the data?

- Yes
- No

17. What would be your preferred format to access the report?

- Hard copy mailed to you
- Downloadable Report from the website
- Interactive web based tool to customize indicators
- Other *(please specify)*

Appendix B - Semi- Structured Interview Guide:

****You were identified and selected to participate in this study because of your involvement in the STOP HIV/AIDS project. We feel like you would have extensive and detailed knowledge on the project, more specifically, the quarterly monitoring reports. The questions I will be asking today will mainly focus on the use of monitoring reports and the role they play in informing strategic planning.****

Interview Questions

A - Intro – Profile of individual responding

- To begin, could you tell me a little bit about your role at the [Health Authority/}
- How would you describe your role in relation to the STOP/HIV AIDS project?
- How long have you been working in your current position?
- What was your role at the HA before you began working on the STOP project?

- What other ongoing projects at the HA are you involved in?
- How much of your time would you say that you spend working on STOP?

B - HA perceptions of *STOP HIV/AIDS* project goals

- How would you describe the goals of the *STOP HIV/AIDS* project?
- How would you describe your success in achieving these goals to date?
- How would you measure success in relation to this project?
    - Why?

***** *In this next section I will ask a couple questions pertaining to the use of the monitoring reports. As you know monitoring reports are used as a quality improvement and evaluation tool and are overseen by the BC-CfE. The reports are issued every 4 months about six weeks after the end of each quarter. We would like to explore and understand how the reports are used, the process in place to review the reports and how useful they are to the STOP HIV/AIDS team. As such, I'd like to ask some questions next about the use of monitoring reports. ****

C - The Use of Monitoring Reports by HA

- What would you describe as the purpose of the quarterly monitoring reports?
- What happens when the new quarterly report comes out?
- Within your team, what sort of process is in place within to review the monitoring report use as a team?
    - Has this process changed over time?
    - If so, in what way?
- Within your team, what sort of process is in place within to respond to the monitoring report use as a team?
    - Has this process changed over time?
    - If so, in what way?

- Could you tell me a little bit more about who is responsible for reviewing quarterly reports within your health authority?
    - How often are reports reviewed as a team within the quarter?
- How are quarterly reports disseminated and circulated within your health authority?
    - How, if at all, are they disseminated beyond your HA?

*** *Monitoring reports play a vital role in informing policy making processes. Strong evidence originating from monitoring reports can lead to informing the decision and choice of policy, forecasting the future and evaluating policy impact. In this section I will ask question regarding the role monitoring reports play in informing strategic planning for the STOP HIV/AIDS project.* ***

D - Role of Monitoring Reports in Informing Policy Decisions

- Could you tell me a little bit more about how quarterly reports have been used to inform planning and assessment?
    - If they haven't, what do you perceive would be the role the reports would play in informing decisions?
- To what extent do quarterly reports help support the progression towards *STOP HIV/AIDS* project goals?
- I understand there was a short period after the STOP HA teams were created before the Quarterly Reports were introduced. Can you tell me a little bit more about the decision-making process around TasP implementation at that time?
    - How has it changed since then?

**** So we've talked broadly about the way that you interact with the Reports and how it influences your decision-making. We're very interested to learn more about your perspective on the specific indicators and to what extent you feel they are sufficient in meeting your needs. I've brought a copy of the latest STOP Quarterly Monitoring Report with me here. As you know, there are 13 indicators in the report, outlining various HIV-specific indicators. Each section stratifies the overall indicator by gender, age group and exposure category. These indicators are intended to help guide and inform development of future interventions and programs. As such, I'd like to ask some questions next about your overall understanding of the performance indicators and their significance to your Health Authority ****

E - The overall understanding of the HA led teams of the performance indicators

- What section of the report is most significant to your priorities at [health authority] right now?
    - Is there a specific indicator within this section that you pay more attention to?
    - *[Is the indicator stratified?]* What is your perspective on the value of the stratification?
    - What (if any) other stratification would you like to see?
- What section of the report is least significant to your priorities at [health authority] right now?
    - Is there a specific indicator within this section that you feel is particularly problematic?
    - *[Is the indicator stratified?]* What is your perspective on the value of the stratification?
    - What, if anything, do you think would make this indicator more useful to your decision-making process?

- Which indicators do you think are difficult to understand?
    - What aspect of the indicator is most confusing?
        - [presentation/construction/thematic focus]

F - How can Monitoring Reports be improved?

- How could the *STOP HIV/AIDS* monitoring report be improved to increase its use and its impact on strategic planning and decision-making?
    - *Focus and content of report on the whole?*
    - *Section?*
    - *Indicators?*
    - *Strata?*

Closing Question

- Are there any other thoughts about the construction and use of the Quarterly Monitoring Reports that you wanted to share?

*** That's the end of the interview. Thank you for your time***

Appendix C – Breakdown of participants:

Role	Affiliation
Epidemiologist	Fraser Health
Medical Health Officer	Fraser Health
Epidemiologist	Island Health
Medical Health Officer	Island Health
STOP & STBBI Manager	Island Health
Regional Director for Prevention	Vancouver Coastal Health
Epidemiologist	Interior Health
STOP Coordinator	Interior Health
Regional Manager of HIV & HEP C	Northern Health
Regional Navigator for HIV and HEP C	Northern Health
Physician	Provinvial Health Services Authority
Evaluation Manager	Pacific AIDS Network

Table 1 – Breakdown of interview participants

Table 2 – Breakdown of indicators in quarterly monitoring reports

INDICATORS	DATA SOURCE

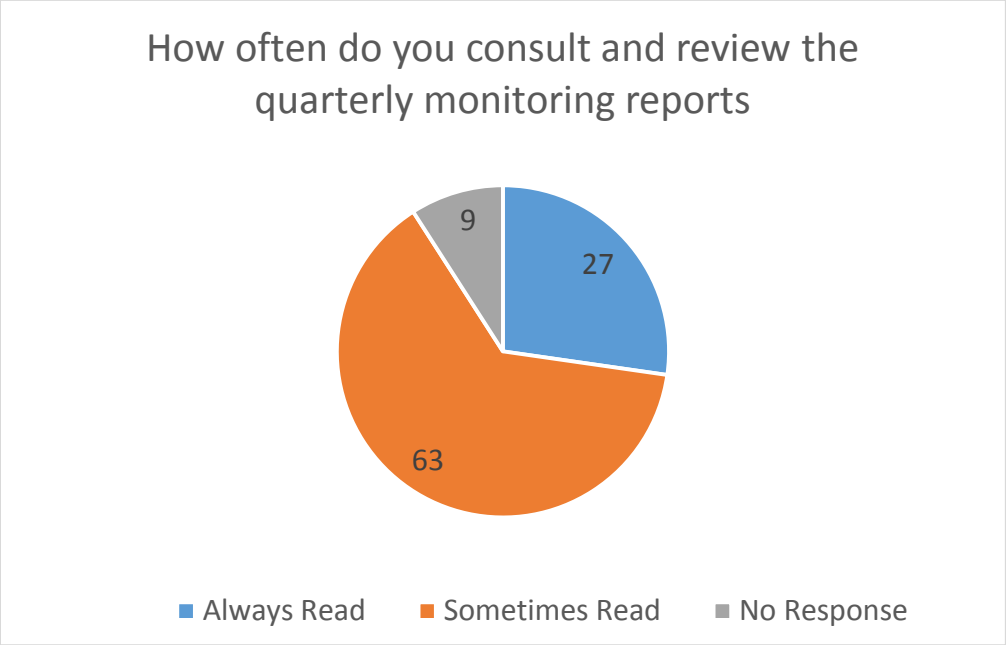
INDICATOR 1. HIV TESTING EPISODES	The number of HIV test episodes and point of care (POC) HIV tests conducted each quarter in BC	BC-CDC
INDICATOR 2. HIV TESTING RATE		BC-CDC
INDICATOR 3. NEW HIV DIAGNOSES	Trends in HIV diagnoses by gender and exposure category are described	BC-CDC
INDICATOR 4. STAGE OF HIV INFECTION AT DIAGNOSIS	Classification of stage of HIV infection	BC-CDC
INDICATOR 5. HIV CASCADE OF CARE	The Cascade of Care provides a picture as to where deficiencies lie in the delivery and uptake of HIV-care	BC-CfE; BC Vital Statistics database; British Columbia Ministry of Health
INDICATOR 6. PROGRAMMATIC COMPLIANCE SCORE (PCS)	The Programmatic Compliance Score (PCS) is a summary measure of risk of future death, immunologic failure and virologic failure from all causes for people who are starting ART for the first time	BC-CfE
INDICATOR 7. NEW ANTIRETROVIRAL THERAPY STARTS	The number and proportion of new HIV treatment initiations and the number of active and inactive DTP participants	BC-CfE
INDICATOR 8. CD4 CELL COUNT AT ART INITIATION	CD4 Cell Count at ART Initiation of ART-Naïve DTP Participants in BC	BC-CfE
INDICATOR 9. ACTIVE AND INACTIVE DRUG TREATMENT PROGRAM (DTP) PARTICIPANTS	Distribution of People on ART for BC and Active and Inactive DTP Participants	BC-CfE
INDICATOR 10. ANTIRETROVIRAL ADHERENCE	Trends in prescription refill adherence levels for individuals in	BC-CfE

	their first year of treatment are shown	
INDICATOR 11. RESISTANCE TESTING AND RESULTS	Present trends in cumulative resistance testing by different resistance category	BC-CfE
INDICATOR 12. AIDS-DEFINING ILLNESS	AIDS cases per quarter	BC-CfE
INDICATOR 13. HIV-RELATED MORTALITY	HIV-related deaths	BC-CfE; BC Vital Statistics database; Statistics Canada

Appendix D - Survey Results

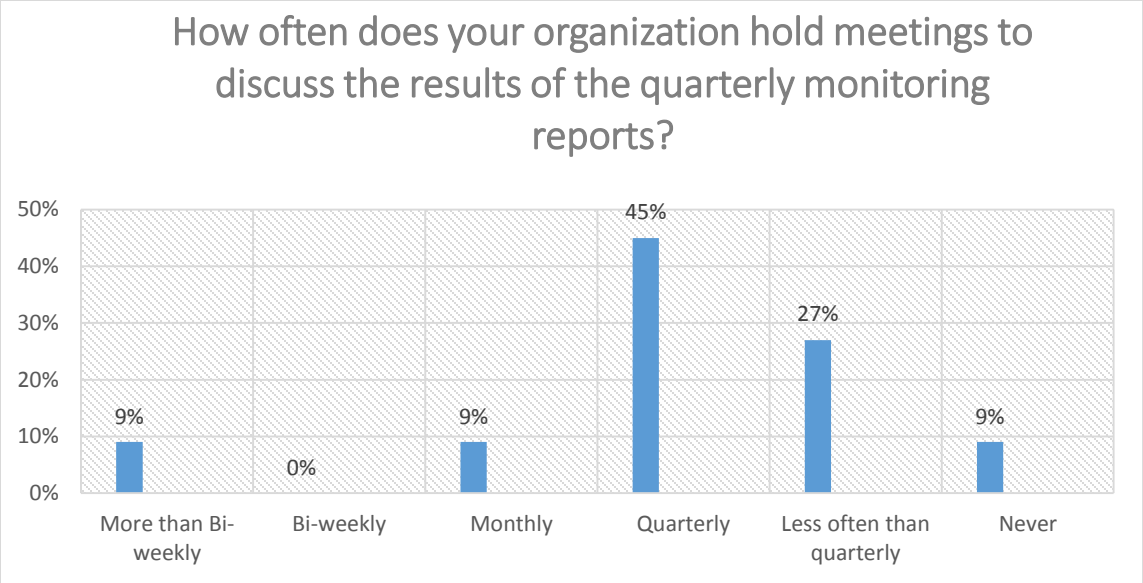
1. How often do you consult or review the quarterly monitoring reports?

Always Read	63%
Sometimes Read	27%
Never	9%



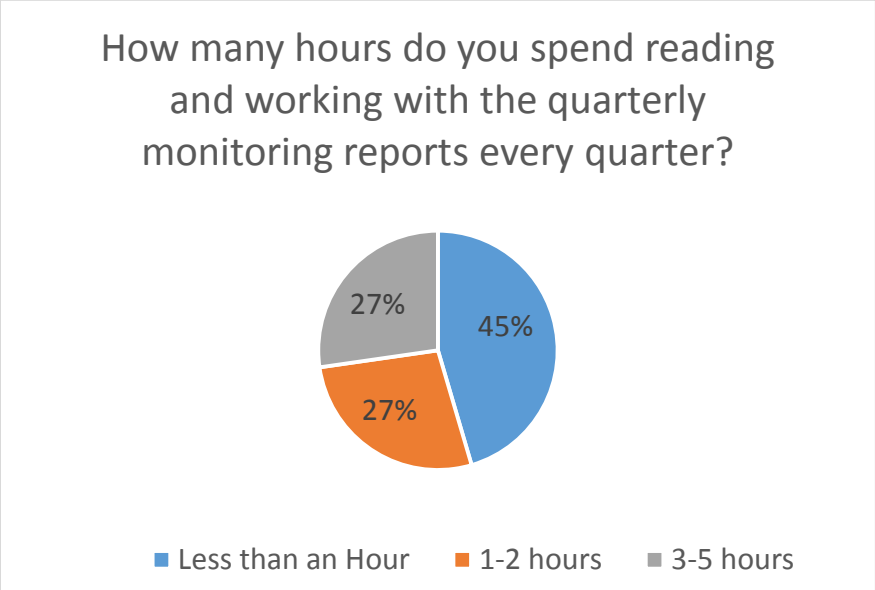
2. How often does your organization hold meetings to discuss the results of the quarterly monitoring reports?

Quarterly	45%
Monthly	9%
Less often than quarterly	27%
More often than Bi-weekly	9%
Never	9%



3. How many hours do you spend reading and working with the quarterly monitoring reports every quarter?

Less than an hour	45%
1-2 hours	27%
3-5 hours	27%



4. On a scale of 1-10 with 10 being “very useful”, how useful are quarterly monitoring reports to your organization?